

“I am not going to have to go somewhere where I am completely dependent...I can still maintain some self reliance or some independence and be of help to others and I really think this is the generation that is going to know about doing that.”

*Baby Boomers are aging...
Do they know what to do?*



Like the United States, Arizona is not only growing but growing older as well. By 2040, the state’s population is expected to reach 9.8 million, of which 2 million will be older than age 65—a 169 percent increase among seniors in only four decades. This expected growth will mean a burgeoning need for long term care programs, beginning with the Baby Boomer generation. Are they armed with the information to make good decisions?

Research indicates America’s Baby Boomers are so consumed with day-to-day life that they’ve hardly considered their own long term care needs. One 1997 study in Minnesota points to a Baby Boomer sense of invincibility, a conviction that they probably never will need long term care. Even among those with a family member using the system, the experience hasn’t helped much—there is confusion, a lack of planning and a lack of knowledge. Are Arizona’s Baby Boomers any different? Not according to recent research.

*Arizona Long Term
Care Project*

The Arizona Long Term Care System (ALTCS) is part of the Arizona Health Care Cost Containment System, the state’s Medicaid program. While ALTCS serves only about 5 percent of those served by AHCCCS, it consumes up to 30 percent of the AHCCCS budget.

To determine if Arizona’s long term care system in general and ALTCS in particular are meeting the public’s needs, AHCCCS established a Long Term Care Project with two primary goals:

- 1. To understand how Baby Boomers view the overall long term care system in Arizona, and what services are important to them.
- 2. To assess consumer satisfaction with case management, doctors and services under ALTCS, both in home and community-based settings and in nursing facilities.

The research, conducted by Health Services Advisory Group in partnership with AHCCCS, included reviews of systems in other states, focus groups and a telephone survey. The focus groups included one with Baby Boomers who had long term care experience in Arizona, and a second with those who didn’t. The telephone survey involved 1,031 current users of ALTCS services, some of whom are also Baby Boomers.

Seven Policy Directions

The results were compiled into seven policy directions to guide state leaders as they reform Arizona’s long term care system in general and improve ALTCS in particular.



This report has been a joint effort of three organizations: AHCCCS, HSAG, and Flinn Foundation. The intent has been to define the issues and propose viable options for policy-makers regarding long term care in Arizona.

Additional copies can be obtained from the AHCCCS website at www.ahcccs.state.az.us.

- Long Term Care:
- Now and the Next Generation:
- Final Report
- Final Report Summary
- Baby Boomers: Who Me?
- What the Consumers Say
- What the Experts Say
- Survey Data Book

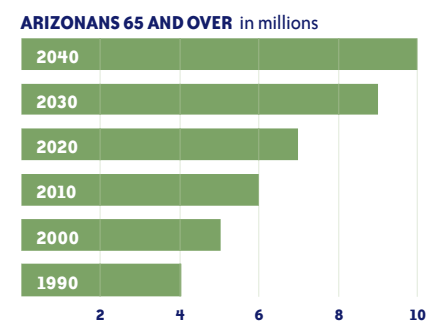
2001
Final Report Summary
Long Term Care
Now and the Next Generation



I

Who needs better long term care education and information?

Seniors, Baby Boomers, Gen Xers—everyone. Research participants either had no real sense about where to go for information, or their understanding of long term care was shallow. The few who had looked for information said they were frustrated because they couldn’t find it, or what they did find was not easy to understand.



POLICY DIRECTION:

1. **EDUCATE, EDUCATE.** Specifically, pilot a long term care education outreach program through human resource departments in a variety of businesses.
2. **FORM PARTNERSHIPS** to ease the flow of long term care information:
 - Create a web site among state agencies such as AHCCCS, the Department of Health Services and the Department of Economic Security to centralize information.
 - Centralize information at a physical location and staffing the site to answer questions from the public.
 - Establish a collaborative effort among state agencies and private organizations to distribute written information.
3. **PROVIDE INFORMATION** that is culturally sensitive.

2

What should be done to help Baby Boomers plan for long term care?

A lot. Participants of both focus groups said they had put little thought into long term care for their parents, let alone themselves. They did not understand who would pay for the service when they needed it. Those with some long term care experience said that all too often they had waited until a family member was in a crisis before seeking help.

POLICY DIRECTION:

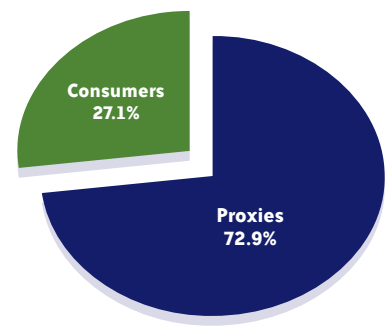
1. **DEVELOP AN AWARENESS CAMPAIGN** to educate Baby Boomers about the need to plan, much as they already do financially for their retirement. The campaign could involve state government, businesses, the long term care and health care industries, social service agencies and non-profit organizations.
2. Give decision-makers and the public a **BETTER UNDERSTANDING** of long term care financing, the makeup of the population currently receiving services and the impact on our communities.
3. **HOLD WIDE-RANGING DISCUSSIONS** about the role of government in providing long term care services.

“Most people of color don’t really use a lot of nursing homes. We bring them home with us and now days we can’t. I work and my husband works...”

3

Who is the ALTCS “customer”?

After surveying 1,031 ALTCS consumers, one result was surprising: 752 of them, or 73 percent, were proxy respondents, while only 279, or 27 percent, were actual “customers” enrolled in the program. What does this show? That proxies, or caregivers, are a valuable source of information because they are so involved with the actual user. This finding has implications for the non-ALTCS population as well.



POLICY DIRECTION:

RE-THINK THE DEFINITION of “customer” when considering the future of ALTCS. State policy-makers should:

- Recognize that proxies are key customers of ALTCS.
- Perform a customer analysis of proxies.
- Determine whether future surveys should be modified for proxies’ input.

Health care leaders can follow a similar approach for the non-ALTCS community.

4

How can consumers and proxies continue to give their input?

There is no question that input from ALTCS consumers is important to help identify which public policy issues should be tackled first.

POLICY DIRECTION:

CONSUMER INPUT can be facilitated if state policy-makers:

- Develop a survey center that can be used by long term care contractors, health plans and state agencies that deal with long term care and aging services.
- Share the cost of operating this center among long term care contractors, health plans and state agencies.
- Standardize the way surveys are worded and conducted so there is comparable feedback.
- Develop a strategic plan to address issues gleaned from continuing input.

“If you don’t know the language, if you don’t know who to go to from the get go, there is very little help that any one agency will give you in order to tag you into another agency. So it is not a central operation at all.”

5

Do consumers really want to choose their health plan?

For the first time, AHCCCS is offering ALTCS members a choice of managed care organizations to serve them, starting with Maricopa County in 2000 and the rest of the state in 2001. The project’s survey of ALTCS members came about largely because of this opportunity to choose. Forty-six percent of survey respondents underscored this change by emphasizing they wanted to choose who served them.

POLICY DIRECTION:

CHOICE IS IMPORTANT. These surveys give the state the chance to see why people choose a health care plan, and why this choice is important to them. A future survey and report will give better direction to establish the best benchmarks for improving satisfaction.

6

How can AHCCCS promote the broader choices of ALTCS services?

It is clear from the survey that consumers are more satisfied with home and community-based care than with nursing facilities, although satisfaction in both settings is high. Consumers also want to participate more closely in directing their care.

POLICY DIRECTION:

THE STATE CAN PROMOTE the following:

- Tell consumers and family members that “long term care” no longer means the only option is a nursing facility.
- Re-evaluate how money is allocated for long term care to encourage more home and community-based services.
- Offer providers more information about choices and consumer needs.
- Redefine which home and community-based settings and services can be offered to the member or the caregiver.

7

How did the Maricopa County Long Term Care Plan rate?

Overall, very well. Consumers were either very satisfied or satisfied with their doctors, case managers and care givers in either home and community-based settings or nursing facilities. However, the ease with which doctors, caregivers or case managers could be reached received lower ratings.

CONSUMERS’ SATISFACTION WITH PROVIDERS

case manager					93%
HCBS caregiver					93%
NF carefiver					90%
doctor					84%

CONSUMERS’ OPINION OF DOCTORS

considers culture					89.0%
shows respect					85.3%
listens to consumer					83.1%
provides help					80.3%
involves consumer					79.7%
reachable					78.6%

POLICY DIRECTION:

RESPECT, AVAILABILITY and helpfulness are key.

- Show doctors, caregivers and case managers how to be more available.
- Help doctors become more involved in the consumer’s long term care services. Specifically, doctors should:
 - include the consumer or proxy in more decision-making,
 - listen more,
 - be more accessible,
 - be more respectful and
 - provide more help.

CONCLUSIONS

Baby Boomers need much more education and information about long term care in Arizona.

Overall consumer satisfaction with ALTCS services is high and the system is working well, but there is much left to do.

Choice among consumers is an important consideration, but we need a better understanding of why individuals want this choice.

All participants in this research clearly want a comprehensive approach to deal with an increasing demand on long term care services in Arizona.